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ABSTRACT

The Centers for Disease Control (CDC) has begun a program for the prevention of disabilities, with one area of focus being developmental disabilities. An objective for the Year 2000 Health Objectives for the Nation has been proposed, stating: "By the year 2000, the prevalence of serious mental retardation (an intelligence quotient of less than 50) will be reduced from 2.7 per 1,000 children to no more than 2.0 per 1,000." Two major approaches for reducing serious mental retardation include reducing its severity among children with clinical disorders associated with serious mental retardation and reducing the incidence of these clinical disorders. Four groups of clinical disorders offer important opportunities to reduce incidence: alcohol-related mental retardation; mental retardation due to psychosocial deprivation; Down Syndrome; and a group of many known causes which account for a small proportion of mental retardation. Maternal use of alcohol in early pregnancy is used as an example to outline an incidence reduction model and possible preventive techniques. CDC will work towards this national health objective in three major areas: technical assistance and support for state and community prevention programs; support for better data and more rigorous evaluation of interventions; and etiologic research. (JDD)

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THE YEAR 2000 OBJECTIVE FOR MENTAL RETARDATION

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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Thank you for this opportunity to speak before the American Association on Mental Retardation about preventing mental retardation and developmental disabilities. The Centers for Disease Control, or CDC, has begun a program for the prevention of disabilities. It focuses on preventing disabilities in three areas: developmental disabilities, injury-related disabilities, and chronic disease-related disabilities. Developmental disabilities were chosen as a priority because they cause a large portion of disability years.

[Slide 1 - Disability Years]

Of the disabilities that begin between birth and 15 years, 5.6 million people are affected and constitute 280 million disability years, roughly one-third of the total.

The CDC Disabilities Prevention Program has been modeled, in part, on the State-based developmental disabilities prevention programs with which many of you have been involved. Back in 1987, two persons on the program today, Dr. Allen Crocker and Dr. Hugo Moser, met with our staff late one evening in Washington, D.C., as we were developing the conceptual frame for the program. To them, we express our gratitude.

The Disabilities Prevention Program will assist States in building capacity for planning, coordinating, and evaluating interventions to reduce the incidence and severity of disabilities. Program activities are, in large part, centered on prevention objectives.

It is likely that one of the Year 2000 Health Objectives for the Nation will address mental retardation. Since these objectives provide policy guidance for the Public Health Service, having an objective on mental retardation represents an important commitment. I will direct my remarks to how the mental retardation objective can be achieved.

In the early 1970s, the President's Committee on Mental Retardation posed the goal of reducing the prevalence of mental retardation from biomedical causes by 50 percent. This goal is laudable, but there has not been, until recently, a way to adequately monitor our progress in this area. The Center for Environmental Health and Injury Control Division of Birth Defects and Developmental Disabilities, building on its experience in birth defects surveillance programs, has developed surveillance methods to measure the prevalence of mental retardation and other developmental disabilities.

We have collaborated with the Georgia Department of Human Resources to carry out the Metropolitan Atlanta Developmental Disabilities Study or "DD Study." This surveillance is derived from many existing record sources in the community (such as public schools and service agencies). The first reports of the data will probably be published this winter.

[SLIDE 2 - Race-Adjusted Estimates - Prevalence of Mental Retardation Among 10-year old American Children]

Using the Atlanta data, we have computed the race-adjusted estimate of the prevalence of mental retardation (defined as an IQ of less than 70) as 8.4 per 1,000 among 10-year-old American children. The prevalence of serious mental retardation, or an IQ of less than 50, among 10-year-olds, is 2.7 per 1,000 Americans.

With the Atlanta DD Study and other surveillance programs that will be established, the United States finally has a reliable score card for monitoring the prevalence of mental retardation. We hope that, in the future, additional epidemiologic centers can be established in different geographic regions throughout the country to collect similar data and that data from some of these centers can be combined to serve as a basis for a national policy. Until then we can use the Atlanta data as a standardized measure, set objectives, target critical interventions, and monitor our progress.

[SLIDE 3 - Year 2000 Objective]

The Year 2000 National Health Objective for mental retardation will probably read as follows: "By the year 2000, the prevalence of serious mental retardation (an IQ of less than 50) will be reduced from 2.7 per 1,000 children to no more than 2.0 per 1,000. This objective will be monitored by race-adjusted rates determined from the Atlanta data.

[SLIDE 4 - Approaches to Achieving MR Objective]

There are two major approaches for reducing serious mental retardation. The first approach is to reduce its severity among children with clinical disorders that are often associated with serious mental retardation. Interventions that are family-centered, multidisciplinary, and community-based can ameliorate the natural course and thus lessen the consequences of mental retardation associated with conditions such as Down syndrome and cerebral palsy. We must learn more about the precise risk factors that are associated with the progression to more severe learning impairment, and what protective factors may be associated with children who have higher IQs.

The other major approach to achieving the Year 2000 mental retardation objective is to reduce the incidence of clinical disorders that are associated with mental retardation. Four groups of clinical disorders offer important opportunities to reduce incidence.

[SLIDE 5 - Opportunities to Reduce Incidence]

They are alcohol-related mental retardation, including fetal alcohol syndrome; mental retardation due to psychosocial deprivation; Down Syndrome; and a group of many known cases which account for a small proportion of mental retardation.

Mental retardation is associated with maternal use of alcohol in early pregnancy. The lower limit of safe alcohol consumption during pregnancy has not been established, but it is clear that most severely affected infants have mothers who were heavy users of alcohol during pregnancy. In a study of pregnancies among women in the middle socioeconomic class, Streissguth and colleagues found that infants born to mothers who reported having two or more drinks a day during pregnancy had, on average, a 7-point decrement in IQ at the age of 7 years. Early intrauterine alcohol exposure is also associated with the fetal alcohol syndrome (FAS), characterized by distinctive facial features, growth retardation, and clinical signs of neurological abnormality. Dr. Neil Holtzman is preparing a monograph for the CDC Disabilities Prevention Program on the adverse effects of consuming alcohol during pregnancy. The monograph will be available later this year.

[SLIDE 6 - Incidence Reduction Model - Alcohol-Related Mental Retardation]

He estimates the prevalence of FAS to be about 1.5 per 1,000 children, of whom about half have mental retardation defined as IQs of less than 70. This means that the prevalence of FAS-related mental retardation is estimated at 0.75 per 1,000. The results of several studies suggest that FAS-related mental retardation represents only part of the mental retardation related to alcohol consumption during pregnancy. Streissguth and her colleagues estimate that about a third of the children with fetal alcohol effect (FAE) also have mental retardation with IQs of less than 70. Thus, we estimate that about 1.3 per 1,000 children have mental retardation related to maternal alcohol use. This means that each year about 4,500 children are born with alcohol-related mental retardation.

[SLIDE 7 - Alcohol-Related Mental Retardation - Possible Preventions]

The many approaches to prevention include (1) health education to (a) increase awareness that alcohol can be hazardous to the fetus; and (b) to discourage teenagers from starting to drink; (2) the identification of alcohol abuse or addiction before conception or in early pregnancy and an increased access to treatment; and (3) legal strategy, such as court intervention, to remove the pregnant women from access to alcohol or to remove the children from the home. To guide policy makers, we must rigorously evaluate outcomes and consider the ethical implications of any proposed interventions. Effective prevention will probably require many concurrent approaches.

In an effort to model the potential opportunities for prevention, I will present a set of speculations that represent educated guesses rather than actual research findings.

[SLIDE 8 - Incidence Reduction Model - Alcohol-Related Mental Retardation]

Recent unpublished data from Streissguth and collaborators suggest that 16 percent of babies born with fetal alcohol syndrome cases have IQs of less than 50. They found that about 4 percent of the children with fetal alcohol effects have IQs of less than 50. This represents a prevalence of serious mental retardation of 0.3 per 1,000 children, or about 15 percent of the children with IQs less than 50. By the year 2000, we would like to reduce the prevalence of serious mental retardation from the maternal use of alcohol by at least 25 percent.

[SLIDE 9 - Down Syndrome Incidence and Births to Women 35 and Older]

Since the early part of this century, the incidence of Down syndrome has been steadily decreasing. The distribution of births, by maternal age, is a very powerful predictor of the risk of babies being born with Down syndrome. In the 1920s, the incidence of Down syndrome was over 2 per 1,000 live births, and now it is about 1.25 per 1,000. This nearly 50 percent reduction in Down syndrome rates occurred because, between the 1920s and 1990, the proportion of live births to women aged 35 and older has decreased from over 15 percent to 5 percent. In the next decade, as the women born in the 1950s move beyond their childbearing years, the proportion of births to older women should decrease even more, and, as a result, the number of babies born with Down syndrome should continue to decrease.

[SLIDE 10 - Incidence Reduction Model - Down Syndrome]

Our estimates for the Year 2000 objective are that now 50 percent of children with Down syndrome have severe mental retardation and that the decrease in incidence and increase in early educational intervention will result in a 25 percent reduction in the prevalence of serious mental retardation among children with Down syndrome.

[SLIDE 11 - Incidence Reduction Model - MR due to Psychosocial Deprivation]

Another major opportunity for prevention is to prevent mental retardation due to psychosocial deprivation. Clearly, psychosocial deprivation can cause mental retardation. However, we do not know what portion of the mental retardation cases in families with psychosocial deprivation are really due to such deprivation or are due to an unknown cause. Estimates of the relative proportions may come from measuring the success of interventions such as comprehensive day care programs for psychosocially disadvantaged children.

For the Year 2000 objective model, we estimate that the prevalence of mental retardation in this combined group, psychosocial deprivation and unknown cases, is almost 5 per 1,000 children and that 30 percent of these children with mental retardation have IQs of less than 50. We believe that the prevalence of serious mental retardation can be reduced by 25 percent through

early educational intervention programs and the prevention of causes that are now unknown.

[SLIDE 12 - Incidence Reduction Model - MR due to Other Known Causes]

We estimate that the group of other known causes of mental retardation accounts for about 1 per 1,000 cases of mental retardation and that 35 percent of these children have serious mental retardation. Important past and ongoing successes in mental retardation prevention include interventions for causes such as congenital rubella, Rh hemolytic disease and kernicterus, lead encephalopathy, phenylketonuria, and hypothyroidism. We need more effective preventive measures for other known causes such as fragile X syndrome, very low birth weight, childhood traumatic brain injury, meningitis, lead toxicity, and Accutane embryopathy. We estimate that, for this group of conditions, the prevalence of serious mental retardation can be reduced by 20 percent. The last two can be completely eliminated by eliminating exposure to lead and Accutane that we have caused.

[SLIDE 13 - Incidence Reduction Model - Summary]

In summary, we can achieve a 25 percent reduction in the prevalence of serious mental retardation by the year 2000. We must build effective intervention programs for the known causes of mental retardation. This must be a collaborative effort for all of us involved with prevention and mental retardation.

Given these opportunities for reducing the prevalence of serious mental retardation, CDC will work in three major areas:

[SLIDE 14 - CDC Program Goals]

1. Technical assistance and support for State and community prevention programs is provided in CDC's new Disabilities Prevention Program. We have supported nine State projects for planning, evaluating, and coordinating prevention activities. In this session of Congress, specific authorizing legislation for the Disabilities Prevention Program has been introduced. The goal of this legislation is to support disabilities prevention programs in all States. Given the necessary appropriation, in the early months of calendar year 1991, we plan to publish another request for proposals and make awards later that summer.

2. The second major area we plan to work in is technical assistance and support for better data and more rigorous evaluation of interventions. I have repeatedly emphasized the need for better data and the need for more rigorous evaluation. The Division of Birth Defects and Developmental Disabilities is uniquely positioned to address these needs. The birth defects surveillance program has 2 decades of experience and has provided

the base for the new program to measure the prevalence of mental retardation and other developmental disabilities.

We are gaining experience in intervention evaluation. For example, we are collaborators in a major clinical trial in China to test the hypothesis that multivitamin supplements taken before conception and throughout early pregnancy reduce the risk of neural tube defects. As you probably know, the results of several case-control studies show that women who use supplements are at a lower risk for having infants with neural tube defects. Women who take supplements may, however, be different from women who do not take supplements in many other ways other than vitamin use. We believe that a randomized trial should be conducted so that we can better draw conclusions on which public health policy can be based. China is one of the few places that this study can be done is a reasonably short period of time.

3. The third program area is etiologic research--that is, identifying previously unrecognized causes of mental retardation. A first step in developing interventions to prevent clinical disorders and diseases that cause mental retardation is to identify the underlying cause. As a field, we have had some great successes. Discovery of congenital rubella as a clinical entity was soon followed by effective immunization programs. Discovery of the blood incompatibility that causes Rh hemolytic disease provided the science base for the necessary intervention to prevent this disease. The Division of Birth Defects and Developmental Disabilities has recently been a major collaborator in identifying the teratogenic effects of Accutane, the controversial oral antiacne medication. Our group is also evaluating the effectiveness of the current patient education strategy that is being used to prevent the adverse effects of exposure to Accutane.

CDC has developed a program in the area of developmental disabilities. We appreciate that the public health significance of these conditions is measured not only by prevalence but also by associated disability years. We will focus our involvement in (1) prevention planning and implementation, (2) surveillance and epidemiologic research, and (3) building relationships so we call all work together to reach the Nation's goals.
In the coming decade, we need to do a lot of work to meet the mental retardation objective for the Year 2000. The inclusion of this objective for the Year 2000 means that reducing the prevalence of mental retardation is a National priority. But people like you, working at the State and community level are really the ones who will make the achievement of the objective possible. The Centers for Disease Control shares the prevention concerns of the American Association on Mental Retardation. Together we can make progress toward this important goal. We see the greatest opportunities are in the areas of alcohol-related mental retardation, Down syndrome, and psychosocial causes. We welcome your ideas about other opportunities.

Before I close, I would like to announce that Dr. Joseph Hollowell has accepted an appointment as Chief of the Developmental Disabilities Branch within our Center. Dr. Hollowell, a pediatrician, is now the Director of the Children's Rehabilitation Center at the University of Kansas, and he has also worked as Kansas Health Officer.

We know, however, we will not be able to prevent all of the disabilities. An equally important goal is for those who have a disability is to be able to live independent and satisfying lives.

Congress has recently passed landmark legislation -- the Americans with Disabilities Act of 1990. When one looks at the history of the annual $120 billion expenditures for those with disabilities, we see almost all of the money going for acute care, institutional rehabilitation, and income maintenance. Precious little is being spent for prevention and even less to develop systems to allow those with a disability to generate his or her own income. Individuals with a disability and their families do not want a handout -- they want an opportunity. We hope to play a part not only in prevention but in providing that opportunity.

Thank you.

Disability Years

Age of Onset	Number of Persons (millions)	Percent of Persons with Disability	Survival (years)	Years of Disability	
				Number (millions)	Percent
Birth-15 yrs.	5.6	20	50	280	35
16-34 yrs.	7.0	25	40	280	35
35-54 yrs.	6.4	23	25	161	20
55+ yrs.	8.7	31	10	87	10

CDC

Race-adjusted Estimates

Prevalence of Mental Retardation Among 10-year-old American Children

- IQ less than 70: 8.4 per 1,000 children
- IQ less than 50: 2.7 per 1,000 children

CDC

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Year 2000 Objective

By the year 2000,
reduce the **prevalence of serious mental retardation in** school-age **children to no more than 2 per 1,000 children.**
(Baseline: **2.7 per 1,000 children aged 10 in 1985-1988.**)

Note: serious **mental retardation is defined as an IQ ‹ 50.**

CDC

4 Approaches to Achieving MR Objective

- Reduce severity
- Reduce incidence

CDC

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Opportunities to Reduce Incidence

- Alcohol-related MR
- Down Syndrome
- MR due to psychosocial deprivation or unknown causes
- MR due to other known causes

CDC

Incidence Reduction Model
Alcohol-related Mental Retardation

Clinical Disorder	1990 Prevalence (per 1,000)	1990 (IQ < 70) Percent of Disorders with MR	1990 (IQ < 70) Prevalence of MR (per 1,000)
Fetal Alcohol Syndrome	1.50	50.00	0.75
Fetal Alcohol Effects	1.50	35.00	0.53
Total Alcohol-related MR			1.28

Data from Streissguth (1990) and Holtzman (1990).

CDC

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Alcohol-related Mental Retardation
Possible Preventions

- Health education
  - Increase public awareness of hazard
  - Discourage teenage drinking
- Periconceptional identification of abuse/addiction
  - Improving access to treatment
- Legal interventions

CDC

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Incidence Reduction Model
Alcohol-related Mental Retardation

Clinical Disorder	1990 (IQ < 50) Percent of Disorders with MR	1990 (IQ < 50) Prevalence of MR (per 1,000)	2000 (IQ < 50) Percent Reduction	2000 (IQ < 50) Prevalence of MR (per 1,000)
Fetal Alcohol Syndrome	16.00	0.24	25.00	0.18
Fetal Alcohol Effects	4.00	0.06	25.00	0.05
Total Alcohol-related MR		0.30		0.23

CDC

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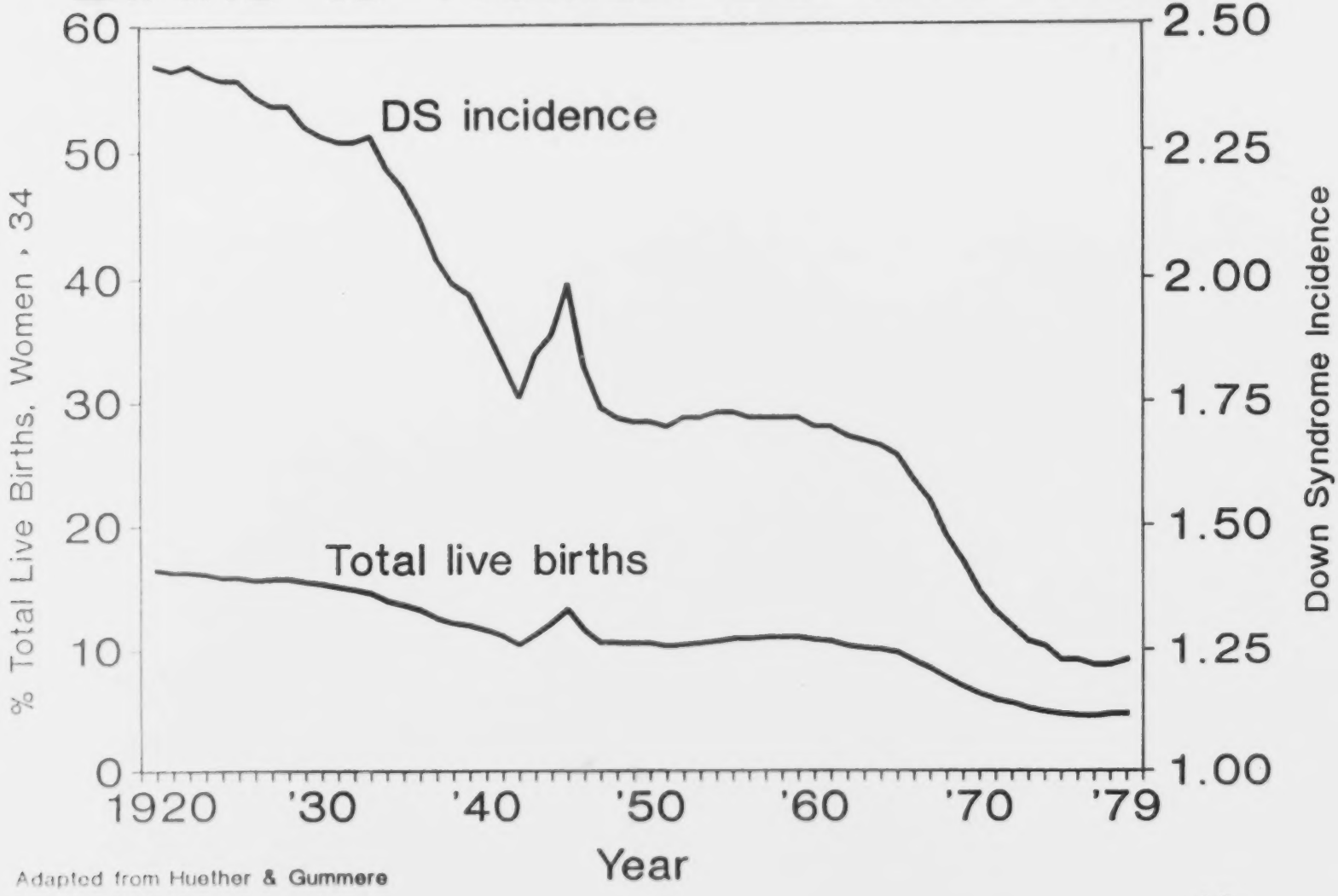
Down Syndrome Incidence and Births to Women 35 and Older



Adapted from Huether & Gummere

Incidence Reduction Model
Down Syndrome

Clinical Disorder	1990 Prevalence (per 1,000)	1990 (IQ < 70) Percent of Disorders with MR	1990 (IQ < 70) Prevalence of MR (per 1,000)	1990 (IQ < 50) Percent of Disorders with MR	1990 (IQ < 50) Prevalence of MR (per 1,000)	2000 (IQ < 50) Percent Reduction	2000 (IQ < 50) Prevalence of MR (per 1,000)
Down Syndrome	1.00	100.00	1.00	50.00	0.50	25.00	0.38

CDC

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Incidence Reduction Model
MR due to Psychosocial Deprivation

Clinical Disorder	1990 Prevalence (per 1,000)	1990 (IQ < 70) Percent of Disorders with MR	1990 (IQ < 70) Prevalence of MR (per 1,000)	1990 (IQ < 50) Percent of Disorders with MR	1990 (IQ < 50) Prevalence of MR (per 1,000)	2000 (IQ < 50) Percent Reduction	2000 (IQ < 50) Prevalence of MR (per 1,000)
MR due to Psychosocial Deprivation and MR due to Unknown Causes	5.13	100.00	5.13	30.00	1.54	25.00	1.15

CDC

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Incidence Reduction Model
MR due to Other Known Causes

Clinical Disorder	1990 (IQ < 70) Percent of Disorders with MR	1990 (IQ < 70) Prevalence of MR (per 1,000)	1990 (IQ < 50) Percent of Disorders with MR	1990 (IQ < 50) Prevalence of MR (per 1,000)	2000 (IQ < 50) Percent Reduction	2000 (IQ < 50) Prevalence of MR (per 1,000)
Fragile X Syndrome VLBW Traumatic Brain Injury Meningitis Lead Exposure Accutane Embryopathy	100.00	1.00	35.00	0.35	20.00	0.28

CDC

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Incidence Reduction Model Summary

Clinical Disorder	1990 (IQ < 50) Prevalence of MR (per 1,000)	2000 (IQ < 50) Percent Reduction	2000 (IQ < 50) Prevalence of MR (per 1,000)
Alcohol-related MR	0.30	20.00	0.23
Down Syndrome	0.50	25.00	0.38
MR due to Psychosocial Deprivation & Unknown Causes	1.54	25.00	1.15
MR due to Other Known Causes	0.35	20.00	0.28
Sum	2.7		2.0

CDC

CDC Program Goals

- Technical assistance and support for state and community service programs
- Better data--rigorous evaluation of interventions
- Identification of previously unknown causes of MR

CDC